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PORTLAND, OREGON

Improving Transitions
to Adulthood for
Young People with
Mental Health Needs:
Youth Experiences and
Recommendations

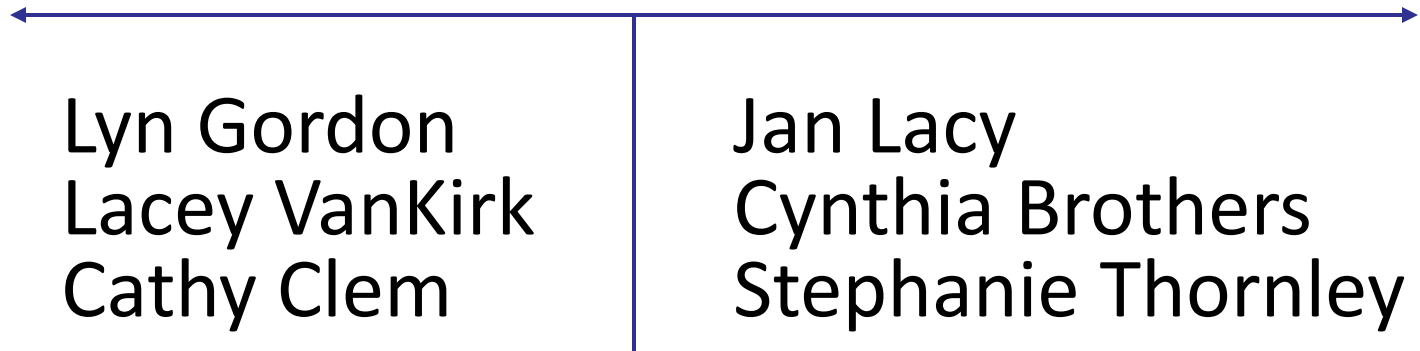
Presented at:

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Research Team

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(Co-Principal Investigators)





Purpose of Presentation

1. To share findings of a participatory interpretive study conducted in two N.W. U.S. metro areas to gain understanding of the experiences and perspectives of youth and young adults (16-24) with serious mental health conditions and families.
2. Focus of this presentation on young people's experiences receiving mental health services and recommendations for improvements to transition supports and services.



Literature Review: Outcomes

Compared to other young people in the transition years in the U.S., those with serious mental health conditions have the most adverse outcomes:

Low rates of high school completion and high rates of unemployment, alcohol and drug abuse, involvement in delinquent activities, unplanned pregnancy, and homelessness (OECD, 2010; Gralinski-Baker, Hauser, Billings, & Allen, 2005; Vander Stoep, Davis, & Collins, 2000).



Research Methods

- Literature review.
- Formation of Portland and Seattle research teams.
- Development of advisory groups of youth/young adults aged 17-24 and family members and consultation to develop focus group questions and plan recruitment.
- Recruitment, hiring, and training of three youth research assistants and family member research assistants.
- Recruitment of youth and young adults to participate in focus groups through contacts with schools, colleges, youth and family support organizations, and mental health agencies.



Research Methods

- 12 separate 90-minute focus groups for youth and young adults with history of using MH services.
- Focus groups held in community locations and at university.
- Trained youth research assistants facilitated groups.
- Participants also completed a pre-focus group demographic questionnaire and received \$30.
- Focus group discussion audio-taped, transcribed, and entered into N6 qualitative analysis software (QSR International, 2002) for analysis.
- After analysis of findings, the team reported preliminary findings to youth advisory groups for member checking and assistance with interpretation.



Focus Group Questions

Questions focused on:

- Youth perceptions of community integration and a successful life in the community for young people with MH conditions.
- Barriers and **supports to community integration.**
- Hopes, goals, and dreams.
- Advice to other young people with mental health challenges in the transition years.
- Ideal supports – **advice to service providers about improving services.**



Data Analysis

- Demographic data were entered into SPSS and descriptive statistics analyzed.
- Focus group transcripts were reviewed by all members of the research team and a preliminary data analysis framework was developed and refined using N6 to manage data.
- All team members reviewed and analyzed one transcript independently then met several times to compare coding rationales and reach acceptable agreement on a coding framework and definitions using consensus decision making.
- After establishing this analytic framework, remaining transcripts were coded independently by research team members.



Analytic Framework

Initial analysis of participant responses were guided by questions:

- Meaning of a successful life in the community.
- Barriers/challenges to life in the community.
- **Supports for a successful life in the community.**
- Hopes/goals.
- Advice (to other young people).
- **Ideal supports (advice to service providers).**



Analytic Framework

Each of these categories was examined in depth in relation to 7 life domains:

- personal;
- family, friends & natural supports;
- living situation;
- school/college;
- employment;
- **service systems & professional supports;**
- community activities.



Youth Demographics

Gender: 35 young men, 22 young women

Age: Range 15-28, median age 19.5

Race/Ethnicity:

- European American: 66%
- African American: 15%
- Multi-racial: 10%
- Asian/Pacific Islander: 7%
- Native American: 2%

Living situation*:

- With parent(s): 42%
- With roommates: 21%
- Alone: 16%
- With extended family: 10%
- With partner/mate: 7%
- Homeless/shelter : 9%

* Includes rounding error



Youth-Reported Mental Health Diagnoses*

• Depression	38%
• Bipolar disorder	28%
• Anxiety	22%
• Attention-deficit disorder or ADHD	17%
• Learning Disabilities	16%
• Substance Abuse	16%
• Obsessive Compulsive	14%
• No response	14%
• Unknown	8%
• Other**	31%

* Percentages add to more than 100% because of multiple diagnoses

**Includes: Asperger's, Oppositional-defiant, Post-traumatic stress, Schizo-affective, and other disorders



Barriers to Success

- **Personal:** Effects of the disorder itself on personal motivation and behavior.
- **All settings:** Stigmatizing attitudes.
- **All settings:** Lack of understanding of MH, especially in high schools.
- **Service System:**
 - Lack of accessible, developmentally appropriate resources.
 - Concerns about “aging out” of services.
 - Lack of appropriate diagnosis and treatment.
 - Not listening to young people.



Service System Supports

Programs focused on meeting the needs of young people in the transition years and offering practical and emotional support.

“...the independent living skills program has helped me just tremendously.”

“[Transition specialist] was the first person I would call when anything went wrong...now I am learning how to step back and look at it and realize that she is there if I need her, the program is there if I need it, but I don't need it as much as I did.”



Service System Supports

Caring, skilled, responsive professionals and mentors.

“My high school counselor was my best support...She was always there, she was really accessible...”

“I compare [name of coach/mentor] to Mr. Miyagi, in the sense that he pushes you, but he cares about you.”

“Whenever I needed to talk, he would be there. He would come by. It was like 4:00 in the morning and he would come over and talk to me.”



Service System Supports



Providers who demonstrate honesty.

“She said, ‘Life is sometimes not fair, get over it.’ That was it. I was like, “Okay, thank you for being honest with me.” It was pure honesty on her part and before that nobody was ever honest.”



Supports: Skills & Practical Assistance

Self-care skill development.

“He had good advice of how to calm myself down, give me some things called cognitive thinking skills that I started using...tools to use to calm myself down and get my mind straight.”

“I had counseling. It made me look at what I did during the week and what I could change if I did something bad, to make it better.”



Supports: Skills & Practical Assistance



Practical Skills.

“They taught me how to manage a checkbook. How to manage money... how to look for transportation, and get a job... how to find a house... how to look in the paper for a job.”



Supports: Information & Strategies

Useful information about mental illness and mental health, giving encouragement and fostering hope.

“She really is awesome. She helped me a lot through a lot of this stuff, and she is still helping me. She just gives me that little glimmer of hope and that’s cool. She understands.”

“They gave me this list of ten coping skills...They were giving me a way out, or at least something to believe in.”



Peer Support

- Awareness and support of others living successfully with mental health difficulties.

“It was an awesome feeling that this is a thing that other people experience...After that I kind of got to the point where I just tell everyone.”

- Involvement in leadership and advocacy activities.

“We will go to legislative meetings, like when there is a bill and it has something to do with youth. We are a group that goes there and figures stuff out.”



Ideal Supports / Advice to Service Providers

Participants' recommendations for access and support:

"A way to access or like a list of psychiatrists near here. It is so hard to figure it out. Someone that can help you find the right one or one who takes your insurance. Counselors the same thing, what are ways to access them, or to find out about them, and get information. Also support groups are needed."

"I guess if I was able to create a university therapy system. I wouldn't make patients feel like they are not supposed to be getting service."



Ideal Supports / Advice to Service Providers



Participants' recommended program changes:

"Somewhere you can go, like when you are about to fall through the cracks, and be kind of taken care of."

"I get the most help out of being able to talk to people who are kind of on my level and just sit down and talk about it."

"Crisis response services."



Limitations of Our Study: Context



- Geographically limited, “convenience” sample – one region of U.S.
- We don’t know how well our sample represents all youth and young adults with MH conditions
- Further studies needed with greater racial & cultural diversity
- Any generalizations must be tentative and we need studies in other social/political contexts
- Need studies with longitudinal follow-up to learn what is helpful over time.



Implications of Findings



Program level considerations:

- Interpretation of findings to occur in local contexts: Does this apply here?
- Tentative ideas:
- Involve young people in program planning and decision making
- Seek youth feedback on services and act on feedback
- Create peer support and mentoring opportunities.



Implications of Findings

Tentative ideas to be considered at practice level:

- Be available, responsive, genuine, friendly, honest
- Recognize young people as the experts on their own experience and needs.
- Examine providers' and families' assumptions regarding youth participation and involvement.
- Facilitate youth self-determination and involvement in leadership and advocacy activities.
- Act in the role of ally as well as advocate.



Implications of Findings: Research

- Participatory research produces findings that are more grounded in the experiences of young people.
- Participatory research and youth-led research is needed to better understand young people's needs and preferences.
- Participatory research takes longer, and requires some additional skills than traditional research.
- Need more research to focus on recovery, success and strengths.
- Community-based research is needed to examine understanding of mental health issues and the outcomes of stigma-reducing strategies.



Appreciation



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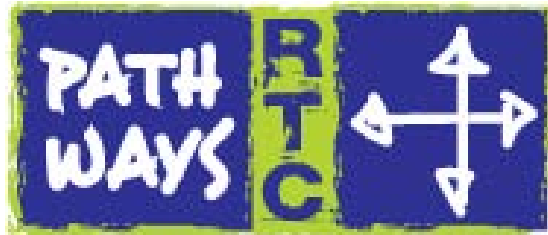
Note: Parts of these findings were reported in a chapter: Kruzich, J.M. & Jivanjee, P. (2010). Using evidence from youths to guide improvements in the mental health system. In M. Roberts-DeGenero & S.J. Fogel (Eds.). Using evidence to inform practice for community and organizational change, pp. 157-176. Chicago, Il: Lyceum Books.



Contact Information



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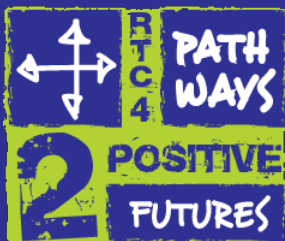


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